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ABSTRACT

Researchers working with the American Indian Rehabilitation Research and Training Center in Arizona have found that culture is important in social research, especially with indigenous people. Community-based participatory research is one approach that has yielded outcomes valuable to researchers and community members. However, ethical concerns must be kept in mind when conducting community-based research. Potentially negative impacts of the research process on indigenous communities must be considered. Researchers have to be aware of the problem of proselytizing Western-based individualism in their work. Researchers working without the input of key collaborators or community experts in Indian communities can be sure that their own cultural biases influence their framing of research questions, their choice of methods, their gathering and interpretation of data, their conclusions, and their recommendations. Researchers in the United States can learn from the experiences of the world's indigenous peoples as they work with governments to define researcher practices that consider culture as essential context in research. In its comprehensive guidelines for the conduct of ethical research in indigenous studies, the Australian Institute of Aboriginal and Torres Strait Islander Studies cited four principles: 1) the need for adequate and appropriate consultation with local communities; 2) sufficient community involvement in and control over the entire research project; 3) demonstrated benefit and sustainable outcomes for the community; and 4) the use of culturally sensitive procedures and methods. (Contains 55 references.) (TD)

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Community-Based Research and American Indians with Disabilities: Learning Together Methods that Work

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Abstract

This paper discusses the importance of culture in social science research and shares knowledge and experience gained through the American Indian Rehabilitation Research and Training Center (AIRRTC). Researchers working through the AIRRTC have found that developing relationships within American Indian communities is cri..al to the success of a given research effort. The present paper explores this factor, along with several others relevant to community research settings that typically are not discussed formally in rehabilitation graduate training programs. For example, the authors discuss the role of a local or on-site coordinator in assisting university-based researchers to identify American Indians with disabilities who can serve as research participants. Local coordinators can also assist researchers in other aspects of the research, such as interviewing, contributing to a final report, and assisting with public dissemination of results. The paper discusses the importance of developing relationships (some of which may develop into long-term friendships) with key collaborators and gives examples of AIRRTC research to illustrate significant points of our experience. Finally, it addresses the importance of networking by rehabilitation researchers to include international collaborations that focus on indigenous issues and disability.

Just before the turn of our new century, psychologists Segall, Lonner, and Berry (1998) asked, "Can it still be necessary, as we approach the millennium, to advocate that all social scientists . . . take culture seriously into account when attempting to understand human behavior?" (p. 1101). They noted that psychology "has long ignored 'culture' as a source of influence on human behavior and still takes little account of theories or data from other than Euro-American cultures. As national societies become increasingly diverse and international contacts become common, psychologists can no longer assume an acultural or a unicultural stance" (p. 1101).

The same can be said for rehabilitation researchers, specifically, as addressed in this paper, researchers whose studies focus on needs and issues affecting American Indians with disabilities. Rehabilitation research with American Indians who have disabilities is intrinsically linked with culture. Researchers at the American Indian Rehabilitation Research and Training Center (AIRRTC) pay attention to culture because not to pay attention to culture would mean not conducting research in American Indian communities (Marshall,

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2001). Culture informs the process of our research, affects our instrumentation, influences our interpretation of results, and contributes to our forms of dissemination.

Since the 1970s, there has been considerable support for the notion that indigenous research should be managed by indigenous people. Indeed, there is a view that nonindigenous researchers have no place in indigenous research (Osborne, 1995). Researchers at the AIRRTC have been both Indian and non-Indian. Regardless of one's position regarding the preferred ethnicity of the researcher, and whether or not she has a disability, we believe in both the value of our work together and the wisdom from the community that informs our work.

Rehabilitation and Research

The AIRRTC, located at Northern Arizona University in Flagstaff, has been in existence since 1983. Funded by the U.S. Department of Education, Office of Special Education and Rehabilitation Services, National Institute on Disability and Rehabilitation Research, it is one of many such organizations in a national network of rehabilitation research and training centers (RTCs). However, only the AIRRTC has as its primary mission the documentation of rehabilitation needs among the indigenous people with disabilities throughout the United States. This documentation is needed to enable state and tribal vocational rehabilitation (VR) programs to develop or improve services that will lead to increased quality of life among American Indians with disabilities. In addition, other rehabilitation agencies and programs, such as independent living services, programs for assistive technology, health services, and rehabilitation education programs, also benefit from AIRRTC research.

Influencing rehabilitation education is indeed an essential outcome of RTC research. Rehabilitation educators, through a core curriculum standardized by a national accreditation body, the Council on Rehabilitation Education (CORE), train those qualified rehabilitation counselors who largely constitute the staff of VR agencies. Bellini and Rumrill (1999) provided an excellent and thorough review of the role of research in rehabilitation counselor education. These authors made a point of acknowledging the need for rehabilitation counselors to apply their knowledge of research in their roles both as practitioners and as active participants in research and program evaluation conducted through and in their agencies' settings. Specifically, Bellini and Rumrill noted that "practitioners can successfully contribute to agency evaluation efforts only to the extent that they appreciate and understand the research that is being conducted" (p. 266).

Our concern? There is no mention by these authors of the role of culture in rehabilitation research. There is no mention of cultural issues being in any way a part of rehabilitation education. Bellini and Rumrill (1999) discussed each of the elements that typically make up an accredited rehabilitation counseling program, including: "foundations of rehabilitation, appraisal process in counseling [assessment], psychosocial aspects of disability, research methods, practicum and internships" (pp. 269-272). In the discussion of curriculum there is no mention of the role of culture. While more than a decade ago CORE noted the need for multicultural issues to be addressed in the rehabilitation curriculum, and this need has been noted by rehabilitation educators (see, e.g., Havranek & Brodwin, 1994; Smart & Smart, 1994), course work involving culture, and certainly course work involving culture and research, does not garner front-and-center attention in rehabilitation education.

Contrast the above "narrow" approach to rehabilitation education with the following notions regarding undergraduate liberal education:

> Liberal education requires that we understand the foundations of knowledge and inquiry about nature, culture and society; that we master core skills of perception, analysis, and expression;

> that we cultivate a respect for truth; *that we recognize the importance of historical and cultural context* [italics added]. Liberal learning is global and pluralistic. It embraces the diversity of ideas and experiences that characterize the social, natural, and intellectual world. To acknowledge such diversity in all its forms is both an intellectual commitment and a social responsibility, for nothing less will equip us to understand our world and to pursue fruitful lives. The ability to think, to learn, and to express oneself both rigorously and creatively, *the capacity to understand ideas and issues in context* [italics added], the commitment to live in society, and the yearning for truth are fundamental features of our humanity. . . . (Association of American Colleges & Universities [AAC&U], 1998).

An additional reason that the cultural context of rehabilitation-related research is so critically important is that rehabilitation educators and the counselors they teach are ethically bound to integrate cultural sensitivity into all aspects of their work, from beginning to end, including research practices. The Commission on Rehabilitation Counselor Certification (CRCC) Code of Professional Ethics for Rehabilitation Counselors, which became effective January 1, 2002, states: "Diversity. Rehabilitation counselors will be sensitive to diversity and research issues with culturally diverse populations and they will seek consultation when appropriate" (Commission on Rehabilitation Counselor Certification, 2002, section H.1 [f], p. 19).

This message, however, needs to come to the profession more emphatically, with more specific direction and strength. It is not enough to have counselors and researchers "being sensitive to" such fundamental aspects of clients' or participants' lives, and only be seeking consultation when or if they think it "appropriate." We must begin to function with research design that is actually *based* in culture, that considers the individual's choices and way of life and their impact on what the counselor or researcher is attempting to accomplish *before* any other factors are addressed (Leung, 2002). We need to stop viewing diversity as a negative factor, listing it along with disability conditions and detrimental barriers. We must begin looking at diversity as a strength, as a defining factor. We must recognize that an individual's ethnicity, language, class, religion, sex, and so on, are cultural "lenses," shaping how we view the world and making each of us unique. Respect for these unique aspects of experience makes an individual stronger and more confident in her or his individual and cultural identity. And respecting these unique aspects of experience, the "culture" of the individual, group, or community, is the only way the researcher can perceive and understand people's life experience, perceptions, and needs with validity. Ethically, cultural factors are integral to the design of research.

Cultural Context: Research in American Indian Communities

The U.S. Surgeon General, in speaking of the need to eliminate disparities in mental health services, stated, "Culture counts" (Daw, 2001, p. 16). Those of us who have worked as clinicians in mental health and with ethnically diverse clients in these and other settings know that "culture counts"—indeed, culture very much matters. Those of us who have conducted research in communities of different cultures know that culture matters. We know that the length of a survey instrument matters. That the content of the questions matters. That the process of obtaining informed consent matters. We know that language matters, that the choice of words, even the choice of synonyms, matters. Regarding the latter point, Brown (1987) noted:

> A writer can create and develop a character through her or his use of dialogue. An upper-class person will draw from a more Latinate word pool and use more subordinate clauses and longer, less volatile speech rhythms. A

> character from the lower classes will use more Anglo-Saxon words, much more colorful speech patterns and shorter, staccato rhythms unless this character is from the American South. In that case, rich and poor alike are more prone to use the rhythm of the King James Version of the Bible. Here again, the poor character will employ more Anglo-Saxon words and will probably be more emotionally direct. . . . Synonyms allow us shadings of class and meaning that can be textured. *They can be felt, not just heard* [italics added]. . . . "If you've fallen through the ice you scream "Help!" not "Aid!" In times of greatest danger or heartbreak even the most aristocratic of people will revert to Anglo-Saxon (p. 13).

So we can say not only that culture "matters" but that culture is actually a "matrix" involving language, for example, as just one aspect of a culture's expression. If research with American Indians who have disabilities fails to take culture into account from the very outset, our understanding of the people and the communities we study will be the less valid for that failure.

Research in the Community

Community-based researchers acquire their knowledge from a variety of disciplines such as anthropology, cross-cultural psychology, and public health. Research processes, as described earlier, are driven by cultural dictates and the context of a given community as well as by theories about research and about working with people. Scholars working with American Indians have much knowledge to share with researchers (Trimble & Medicine, 1993); such cultural information can provide essential context for designing research. Practitioners in various disciplines working with American Indians can also inform researchers regarding both cultural concerns and appropriate research methods (McDonald, 2000, 2001).

For the first author of this paper, "best practices" in research often overlap, such as those derived from theories espoused by feminist researchers (Du Bois, 1983; Gatens-Robinson & Tarvydas, 1992) and inclusive research practices such as the *Consumer Concerns Method* discussed below. Du Bois, for example, initiated her exploration of science and values by stating that "Science is *not* 'value-free'; it cannot be. Science is made by scientists, and both we and our science-making are shaped by our culture" (p. 105). She observed that

> in its conceptions of science and knowing, our society has embraced and reified the values of objective knowledge, expertise, neutrality, separateness, and *opposed* them to the values of subjective knowledge, understanding, art, communion, craft and experience. . . . Objectivity and subjectivity are modes of knowing, analysis, interpretation, understanding. They are not independent of each other, and should not be" (p. 111).

Du Bois went on to suggest that it is the "*synthesis* of subjectivity and objectivity that is the source of intellectual power and responsibility—and truth" (p. 113).

The AIRRTC Experience

AIRRTC community-based research utilizes the principles of Participatory Action Research (PAR; Graves, 1991, 1992; Bruyère, 1993). An important early resource directing our research was the Consumer Concerns Method, a procedure for securing the input of persons with disabilities through working groups that design a given survey instrument, the survey itself, and a public meeting disseminating the results of the survey (Fawcett, Seekins, Wang, Muiu, & Suarez de Balcazar, 1982; Fawcett, Czyzewski, & Lechner, 1986). However, O'Connell (1987) recognized that the method required some adaptation for use with American Indian communities and so proposed to "assess" the adapted model.

Research to assess the proposed model was implemented by AIRRTC researchers Marshall, Johnson, Martin, & Saravanabhavan (1990; see also Marshall, Johnson, Martin, Saravanabhavan, & Bradford, 1992) in the Denver metropolitan area. The model was then replicated by AIRRTC researchers in the Minneapolis-St. Paul metro area (Marshall, Day-Davila, & Mackin, 1992). The Texas Rehabilitation Commission learned of these studies and requested that the AIRRTC carry out this model of research in Dallas-Ft.Worth (Schacht, Hickman, Klibaner, & Jordan, 1993) and then in the Houston Metropolitan area (Schacht, Morris, & Gaseoma, 1993). This AIRRTC version of the model was adapted by other researchers for use with a rural, reservation-based population (McAlees & Pichette, 1993; Pichette, Berven, Menz, & La Fromboise, 1997), and also by AIRRTC researchers for rural reservation needs assessments regarding independent living outcomes (Sanderson, Schacht, Clay, & Maul, 1996).

One important AIRRTC modification of the original Consumer Concerns Method involved using interviews rather than the pencil-and-paper format (involving distribution of the survey by mail to all identified persons with disabilities in the community, with respondents then completing the survey on their own). Recognizing that the written format sent by mail would not be feasible with American Indian populations, because mailing lists of American Indians with disabilities were generally not available and because it was anticipated that the response rate would not be good, O'Connell (1987) proposed to administer the instrument in face-to-face interviews with American Indians with disabilities "in order to increase the level of participation and to insure that the interviewees understand the questions" (p.146). This method seemed the best way to gain both trust and participation in order to obtain valid and reliable information.

The AIRRTC sampling design involved "snowball" sampling (by necessity, as other sampling methods were not practical), beginning with known or identified members of the community who had disabilities. Local media and word-of-mouth were used to recruit participants. In addition, each participant was invited to supply the names of other community members with disabilities who might be interested in participating in the survey.

To conduct the interviews, the AIRRTC recruited and trained American Indians from the community involved in the study, and hired a local American Indian research coordinator to supervise the work of the interviewers. These procedures, consistent with the principles of PAR, were pragmatically designed to produce the best results.

Several types of research questions were addressed. For example, the AIRRTC investigations gathered information on disabling conditions and limitations, Indian people's use of existing services from a variety of agencies, their perceived barriers to needed services, and extensive demographic information. AIRRTC research involved an advisory committee, consisting of both service providers and consumers, throughout the course of the projects. The committee's task was to ensure that the survey questionnaire would produce information that would be truly helpful in improving services for American Indians with disabilities in their service areas, as well as to ensure that the questions were culturally sensitive and appropriate.

The detailed results of AIRRTC community-based research have been presented in publications cited in this paper. We have found that community-specific needs assessments provide important, customized and prioritized information about the needs of American Indians with disabilities. The communities studied have, in turn, used this information in grant proposals (e.g., Lunz, 1998) and for other community development purposes. Another benefit is that in the process of conducting studies, service providers in diverse agencies previously unknown to each other discover common interests and can work together to develop common solutions to

problems documented through AIRRTC research.

There are important methodological issues to be considered in conducting community-based participatory research in American Indian communities. One cannot expect to "jet in" and have everything organized in a few hours. Indian people have often had unpleasant experiences with outsiders asking questions. AIRRTC research experience echoes that of Preloran, Browner, and Lieber (2001) who noted, "Our experiences proved that rapport is as vital to recruitment as it is to qualitative research itself. . . . Our recruitment strategies required relatively extensive and uninhibited access to the potential candidates prior to securing their consent. Candidates who agreed to enroll in the study said they felt we were genuinely concerned about them as individuals and sensitive to the realities of their lives, and they wanted to reciprocate" (pp. 1838-1839).

Preloran et al. (2001) reported that "although in our case recruiters' ethnic backgrounds matched those of participants, this does not mean that our recruitment strategies were successful for this reason alone. Researchers from cultural backgrounds that are different from those of study participants can also develop recruitment strategies that are sensitive to participants' ethnic backgrounds" (p. 1840). For the AIRRTC, "case recruiters" in community-based research most often take the form of "key" collaborators who serve a variety of functions.

The Role of "Key" Collaborators or Community Experts

It is of vital importance to develop collaborative relationships with members of the American Indian communities in which one is doing disability-related community-based research. Researchers who attempt to breach cultural "walls" without the intercession of a community member will be hard pressed to find adequate and appropriate participants for their studies. The AIRRTC experience has been that American Indian key collaborators who are associated with and respected by the community being studied, persons who have expertise in their community, are indeed essential to the research process. Clearly, research results can also be biased by actions taken as a result of key collaborator involvement; thus, in developing relationships within a given community the researcher must bring skills in identifying, approaching, and aligning with a representative variety of key collaborators.

Key collaborators serve as liaisons, facilitators, instructors, guides—and, at times, friends—for the researcher, interfacing with tribal authority should the study be taking place on a reservation, or with community organizations in an urban setting. Because key collaborators, as Indian people, understand and are integrally involved in the research project, they can present the ideas and describe the process to those groups and individuals on a different level than can the non-Indian researcher. They can gain trust and cooperation where the researcher alone might meet only passive resistance or polite incomprehension. They will also educate the researcher regarding attitudes of the participants and expectations—both positive and negative—of the individuals and groups involved. They will instruct the researcher on the need to have frequent and consistent involvement in community activities, which will create a presence of the researcher in the community and increase the comfort level of those involved in the study.

In addition, key collaborators can be extremely valuable in helping the researcher avoid pitfalls which are frequently encountered when working with people from cultures significantly different from one's own. For example, it is imperative that the researcher be, and be perceived as, interested and curious, but not nosy or judgmental. If for any reason the researcher is perceived as being arrogant or self-important, or displays callousness or disrespect toward the individual, group, family, or extended family, that particular interview

will go nowhere, and this problem will quickly be made known to other potential participants. Cooperation must be garnered through polite requests, not officious orders. Confidentiality must be carefully guarded at all times, which can be a challenge considering the closeness of the community and interlinking relationships.

Key collaborators, simply by virtue of being American Indians, will be able to act as buffers for the researcher and significantly smooth the way for valid information sharing. An Indian person is much more likely to place trust in another Indian person because of their shared knowledge, the shared understanding of being Indian people in a non-Indian world, and consequently the fear of being disrespected or looked at with contempt is significantly lessened. A key collaborator can function as a protective shield, softening the impact and anxiety of relating very personal and private information. A key collaborator will help with explanations, bridge language barriers, and facilitate mutual understanding by being able to relate information to the Indian participant in ways only another Indian person would understand—serving as a two-way filter of communication, able to convey the true meaning of the information sought and given.

Finding appropriate participants is not always an easy task in any research project, and frequently there can be problems finding a sample as large as the researcher might hope for. This can be especially true in American Indian communities in general, and if other qualifying issues such as disability are put into the mix the sample narrows even more. Researchers may find that the participant list is small at first, then begins to grow as positive experiences and interactions are reported by word of mouth within the community. The key collaborator will know where to look for participants, and can encourage participants to contact other individuals they know who might be appropriate for the research. Consequently, although the usual methods of identifying research participants might not work, even designs calling for a random sample may eventually prove workable (Marshall, Johnson, Wiggins, & Gotto, 1998).

Integral to the process, then, is finding American Indian key collaborators to work with the researcher and to perform these many and varied activities. While this can be difficult, it is a vital piece in the research process, and must be attended to very early in the process. Frequently, initial contacts within the community can suggest individuals who might be appropriate. Sometimes it is necessary to advertise to find the right person; at other times, word of mouth can suddenly produce exactly the person or persons best suited for the position. However it happens, success in any research project involving American Indians, especially reservation populations, will hinge on the involvement of that key collaborator.

One Example: Eastern Band of Cherokee Indians

Calvin Hill served as an on-site research coordinator for the AIRRTC on the reservation of the Eastern Band of Cherokee Indians. His comments below, prepared for this paper, provide an example of the role of a key collaborator and reveal that valuable outcomes apart from any planned by a program of research can result, even indirectly, from university-community collaborations.

> *The Eastern Band of Cherokee Indians in North Carolina and the Choctaw Tribe in Mississippi participated in a joint qualitative community-based research project sponsored by the AIRRTC, American Indian Family Support Systems and Implications for the Rehabilitation Process (Marshall & Cerveny, 1994; Marshall, Sanders, & Hill, 2001). The study was conducted so service providers could learn how to utilize families in the rehabilitation process. Focus was directed toward the human elements while statistics were ignored. I served as the on-site research*

coordinator on the Qualla Boundary, the reservation of the Eastern Band of Cherokee Indians.

Advantages exist when qualified local Natives are utilized in research projects and are viewed as the determining factor for successful research in Indian Country. Familiarity with the region is a bonus as there are logistical factors to be considered. In the mountains, dense foliage hides driveways, homes, even housing projects from the unobservant. Few signs exist on secondary roads and multiple adjoining roads are unnamed, so caution is recommended to prevent becoming confused and lost. Seven communities are adjacent within our boundary and lines between are crossed often without recognition. Locals take pride in their communities and may resent being mistaken as a member of another community. A person new to the area would show wisdom by having patience and allowing 30 days to familiarize oneself with the region. The service-providing agencies lie scattered throughout the Qualla Boundary. Natives living in the area are familiar with the names of agencies, types of services each provides, and the location of each branch. Advantage lies in knowing hierarchy of agencies and contact persons to seek out for assistance with research.

When making contact with the traditional family, persons with knowledge of Eastern Band of Cherokee Indian customs approach the matriarchal head of family (wife) for permission to interview family. Once permission is granted, a state of goodwill is created between interviewers and family, thus opening doors for communication. A standard courtesy to observe is to sit and make small talk and allow the spokesperson for family to ask the reason for the visit. Many traditional families refuse to relinquish their Native language and retain Cherokee as their primary language. A fluent bilingual person familiar with the three spoken dialects of the Eastern Band of Cherokee Indians is desired to interview a family. One of these, the "Over The Hill Dialect," is supposedly obsolete, though one can occasionally hear it spoken.

It is advantageous for the AIRRTC and other agencies to allow the Native on-site or local research coordinator to perform preliminary home visits and dispel any confusion about pending visits by researchers when approaching the "older generation." Many still harbor deep-seated mistrust of anyone who isn't Native. For the local research coordinator, being visible in a service-providing profession assists in establishing trust and vanquishes fears regarding confidentiality concerns.

Visitations into the communities and homes reveal the struggles entire families endure when providing care to a relative with a disability on a daily basis. A local research coordinator would have knowledge of the plight and history of a given family as contact is made often in the communities. Through use of compassion and humanistic interviewing approaches, light can be brought to problem areas, as well as previously unvoiced concerns and many unresolved issues. Ignorance of available services, false pride, and commitments to provide care alone are at times cited as stumbling blocks that keep families isolated and alienated from needed services.

Active participation in research deemed a turning point in career. *My occupation is to ensure that our elderly, impaired, and the indigent members of our tribe receive the maximum benefits*

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to which they are entitled. I am managing and developing the Supplemental Health Insurance Program (SHIP), a service not in place at the time of the AIRRTC research. Working in conjunction with multiple agencies and service providers ensures availability of needed assistance to raise the standard of living for this population. Utilization of holistic approaches serves to uncover areas of need untouched by other providers. Staff at SHIP use humanistic approaches in service delivery and encouragement is given to show compassion and warmth to all served. As a result, our program is considered a model and viewed in a favorable light by the Eastern Band of Cherokee Indians administration and public alike.

Research with Deaf American Indians

While the AIRRTC has had many successes in conducting community-based research, there are challenges ahead—challenges which must be faced but for which there are no easy solutions. One such area of research involves Deaf and hard of hearing American Indians. There is no literature specifically describing the experiences of Deaf American Indians in relation to learning tribal languages, customs, or traditions. However, there appears to be broad inclusion in tribal activities, ranging from passive observation to active participation (James Woodenlegs, personal communication, 1998; see also Kelley, 2001). Of particular interest is the extent of involvement or inclusion of Deaf American Indians in tribal or local school systems and the effectiveness of vocational preparation for them. Virtually all individuals interviewed by one of the authors (HB) were enrolled in state supported schools for the Deaf rather than in tribal or local schools with large Indian populations. This indicates that their formal educational experiences were based in non-Indian settings and locales.

Demographics of the U.S. American Indian and Alaska Native populations indicate that there has been constant and substantial population increase over the past four censuses (U.S. Census Bureau, 2000). Correspondingly, there is likely to be an increase in the number of Deaf and hard of hearing individuals in these populations. The estimated population of 2,450,000 people identified as American Indian and Alaska Native consists of approximately 95,000 individuals who can be classified as Deaf or hard of hearing. This is a conservative calculation utilizing the standard 2% prevalence rate of deafness among general U.S. populations. The figure could be much higher among American Indians due to high rates of middle ear infections, especially in Alaska where indigenous people often live in isolated places with inadequate medical facilities.

Preliminary research supported by both Gallaudet University's Graduate Research Institute and the AIRRTC is now under way to understand better the education and employment experience of Deaf American Indians—specifically, the quality of the transition from school to work provided by their education. The research calls for a series of interviews with Deaf American Indians between the ages of 18 to 34 and is designed to collect information about their school-based academic, vocational, and extracurricular experiences, whether they had graduated or dropped out of school. Participants have been encouraged to share their perceptions of school-based or community-based transition and career development experiences. Post-school outcomes, such as job-seeking skills, employment competence, and upward mobility experiences are also being collected.

Finding Deaf American Indians who fit the criteria for inclusion in this project has proven to be extremely difficult because most of them are scattered throughout the United States and travel is prohibitively costly. The data collected thus far is insufficient to show definite trends or needs among Deaf American

Indians in the area of school-to-work transition programming and planning. However, the number of Deaf and hard of hearing American Indians appears to be sufficiently large to justify ongoing research on a variety of levels. The research would need to include face-to-face interviews to gain input on participants' perceptions of existing services. Demographics could be collected through direct contact with school districts, tribal offices, rehabilitation services, and other related social agencies. This needs to be done for each tribe.

There is a need to obtain information about the employment status of Deaf and hard of hearing American Indians. Questions need to be asked about types of jobs, job settings, income, benefits, insurance, and related employment concerns such as promotions, accessibility, and salaries. There is a need to find out more about educational programs for Deaf and hard of hearing American Indians, and especially about how well they are prepared for careers, post-secondary education, or both. How many Deaf or hard of hearing students attend tribal colleges or universities? What types of services do they receive? Questions need to be asked about family involvement, communication methods, and ways to support family members in providing for the well-being of their Deaf family members. Questions also need to be asked about the level of support family members need for their own well-being (Marshall & Cerveny, 1994).

Learning with Our Neighbors: Rehabilitation Research in a Global Context

Research processes, and measurement in particular, must take into account the values of a given cultural group. Researchers working with American Indians with disabilities can well learn from other indigenous populations (Marshall & Largo, 1999). American Indian peoples, representing less than 1% of the United States population, have been described as "invisible," and certainly Indian people with disabilities are ignored, left out, or not represented in databases and research designed to address disability in general; Indian people with disabilities are not even represented in databases that include other ethnic minorities with disabilities. This is true, for example, on the government website that specifically addresses race, ethnicity, and disability in the United States (U.S. Census Bureau, 2001).

An awareness of other indigenous cultures in the world "adds to the numbers," expanding our knowledge base and exposing rehabilitation researchers to cultural differences that have an impact on research design. For example, Comas-Días, Lykes, & Alarcón (1998) have studied, among others, the indigenous people of Guatemala and stated that "they offer compelling examples of the struggles of indigenous peoples . . . within the context of multiethnic, multiracial societies dominated by lighter skinned descendants of Spaniards, by U.S. regional hegemony, or by both" (p. 778). These researchers noted that "the individualistic, autonomous self driven by personal concerns has been recognized as being [Western] culture-specific rather than universal" and lacked relevance to the Mayan people with whom they worked (p. 783). Specifically, they reported that for the Maya, "to speak of 'who I am' invokes family, community, the animal kingdom, one's traditions and language, and the earth" (p. 783). The need for researchers to acknowledge the collective as a valid, appropriate, and sometimes even primary unit of measure, reference, and significance would be supported by Lang:

> A further question arises concerning the appropriateness and applicability of the western-based notion of empowerment, which presupposes that rights are exercised and that decisions are made in accordance with the preferences and wishes of the individual, to developing countries. Such an individualized notion of empowerment as espoused by the international disability movement runs contrary to accepted social customs and practices that are found in many developing countries. . . . It is

> surely right to question the efficacy of proselytizing western-based individualism, which runs contrary to the collective and communal or familial patters of decision-making . . . . (Lang, 1998, pp. 7-8).

This collectivistic perspective was mirrored in the indigenous people of Mexico, namely Zapotecs, Mixtecas, and Mixes, with whom the first author has worked (Marshall, Gotto, & Bernal Alcántara, 1998; Marshall, Gotto, & Galicia García, 1998; Marshall, Gotto, Pérez Cruz, Flores Rey, & García Juárez, 1996), and clearly calls for research and measurement that recognize and take into account the collective.

The Aboriginal Experience in Research

Researchers in the United States can learn from the experiences of the world's indigenous peoples as they work with governments to define research practices that consider culture as essential context in research. The Australian Aboriginal people have been described as "simultaneously amongst the most researched and the most disadvantaged peoples on Earth" (Scougall, 1997, p. 460). Some hold that research conducted on Australian Aborigines has been, for the most part, insensitive, inadequate, and inappropriate (National Health and Medical Research Council [NHMRC], 1991); has exploited indigenous communities (Victoria University, 2000); and has merely served to advance the "politics of colonial control" (Dodson, 1994, p. 11). For instance, in the early years of colonization, research was preoccupied with "classifying and labeling" Aborigines (Dodson, 1994, p. 3), representing governmental attempts at "management." Research prior to World War II concerned itself primarily with matters of interest to the science of white Australians rather than to the well-being of indigenous communities (National Health and Medical Research Council, 1991).

In 1986, a national conference on "Research Priorities in Aboriginal Health" provided further impetus for developing ethical guidelines to govern the conduct and funding of research into Aboriginal and Torres Strait Islander health issues. Approved in 1991, these guidelines now form the basis of the National Health and Medical Research Council's ethical criteria for Aboriginal and Torres Strait Islander research. These criteria, although focused mostly on medical research, provided clear procedures for researchers and institutional ethics committees in relation to 1) appropriate consultation prior to the initiation of research, 2) community participation in research, and 3) ownership of the data. Researchers were now required to demonstrate that they had sought advice from appropriate local authorities in the community and that the community considered the research to be potentially useful and sensitive. Written consent was required from the community and such consent was to be based on accessible information, personal discussions, and sufficient time for decision-making. Researchers were now obliged to offer appropriate Aboriginal people the opportunity to assist with the research as paid associates. Communities were to be reimbursed for any costs arising from the research. In terms of ownership, communities were given the right to feedback about the research findings, return of raw data, and control over the publication of results in any format. Involvement of Aboriginal research associates in the publication process was encouraged (National Health and Medical Research Council, 1991).

In 1997, the Aboriginal and Torres Strait Islander Commission (ATSIC), a Commonwealth Government Department controlled by an elected Aboriginal Board, released a document outlining the protocols for undertaking research relating to indigenous people (Aboriginal and Torres Strait Islander Commission, 1997). Based on the need for researchers to respect the maintenance and continuance of Aboriginal culture, these protocols called for researchers to reflect the distinct languages, customs, spiritual beliefs, and perspectives of the particular community under study. In particular, the preference in Aboriginal culture for transmitting knowledge

orally should be respected and the topic of the research must not contravene the wishes, customs, or rights of the people.

By 1999, the Australian Research Council (ARC), in collaboration with ATSIC, had produced a report on the ethics of indigenous research (Australian Research Council & Aboriginal and Torres Strait Islander Commission, 1999). The report recommended that all indigenous research should be based on adequate negotiation with and participation of indigenous people throughout the entire life cycle of the project. It also recommended that all projects should include a training component for indigenous people. At the national level, it was recommended that a sound mechanism should be developed to ensure that research priorities are legitimately those of indigenous people.

In an attempt to integrate the conclusions of these investigations, the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) (2000) produced comprehensive guidelines for the conduct of ethical research in indigenous studies. These guidelines, together with the insights offered by experienced researchers and indigenous research organizations, can be synthesized to produce four major principles for successful and ethical research in indigenous communities. These four principles include (1) the need for adequate and appropriate consultation with local communities, (2) sufficient community involvement in and control over the entire research project, (3) demonstrated benefit and sustainable outcomes for the community, and (4) the use of culturally sensitive procedures and methods.

Culturally Sensitive Methods

Perhaps the most subtle but damaging impact of research among indigenous peoples has been the use of culturally insensitive research methods. Western researchers have often been charged with "hearing, but failing to listen" to indigenous people's communications and concerns (Eckermann, Dowd, Martin, Nixon, Gray, & Chong, 1992). Even though many researchers claim to have cultural understanding, this understanding often only skims the surface of the differences between Aboriginal and non-Aboriginal ways (Kendall & Marshall, 2002).

Consequently, the AIATSIS research guidelines (Australian Institute of Aboriginal and Torres Strait Islander Studies, 2000) recommended that researchers new to indigenous communities undertake training in cultural awareness. For example, it is important to acknowledge the fact that indigenous culture in Australia is transmitted primarily by oral storytelling (Scougall, 1997) and data collection should reflect this method (e.g., narrative interviews, observations). As Bostock (cited in Swan & Williams, 1998) commented, Aborigines have all experienced a "cultural disability" caused by ongoing social disadvantage and a history of majority culture attempts to destroy Aboriginal culture and language. The inability of researchers to respond appropriately to expressions of resentment and bitterness about this only increases the mistrust and suspicion that have prevailed between Aboriginal people and European Australians.

Conclusions

The foregoing discussion makes clear the critical importance of culture in social research, especially with indigenous people. Community-based participatory research is one approach which has yielded outcomes valuable to researchers and community members. However, we must also bear in mind ethical concerns in conducting community-based research. For example, it is important to consider not only the overt benefits of research but also the potentially negative impacts of the research process on indigenous communities (Tapp, Kelman, Triandis, Wrightsman, & Coelho, 1974). Lang brought to our attention the problem of "proselytizing western-based individualism" in service delivery. We know that we bring our own cultural perspectives with us to a given research effort (Segall, et al., 1998).

Researchers working without the input of key collaborators or community experts in Indian communities can be sure that their own cultural biases influence their framing of research questions, their choice of methods, their gathering and interpretation of data, their conclusions, and their recommendations. This "error" takes place regardless of the quantitative or qualitative nature of the research. A research project may begin with a quantitative measure of individual happiness, be validated with a majority culture population that values an individualistic worldview, and then be used to assess degree of happiness for an individual indigenous person from a collective society. Because this person's culture was not taken into account, the "objective," quantitative, and "valid" measure, in fact, could *only* produce invalid results.

Focus on an individual community can be essential for local participation in research, for community relevance, and for community action planning. Individual community focus allows researchers to avoid the problem of overgeneralization of results and can bring credibility to the academic researcher's recommendations for problem-solving in relation to rehabilitation needs. Personal relationships with key collaborators can lead to long-term involvements in professional development, community intervention, and new research opportunities. AIRRTC research experience in the community leads us to support the position statement of our colleagues in public health:

> We recognize the power of *equal* partnerships including community-based organizations, academic institutions, and health agencies. . . . We understand that in order for these partnerships to be equal and for interventions to be community-*based,* community members must participate fully in the identification of health issues and the selection, design, implementation and evaluation of programs that address them. (Community-Based Public Health Caucus, 2002, Vision section)

AIRRTC researchers tend not to be bench scientists. While we support and acknowledge the importance of laboratory science in a variety of fields, we have, as Segall et al. (1998) said of themselves,

> . . .long labored in the field, out there among real people in real places and at real times. . . . What is lost in scientific control of the subject matter is, we believe, more than made up by the enhanced validity, especially, the ecological validity, of our findings. . . . We are often confronted by an uneven distribution across ethnic groups of well-being on the one hand and various kinds of distress on the other, and we sense an ethical imperative not to paper over these inequities with dispassionate research reports. (p. 1106)

And thus AIRRTC researchers are called to write passionately of our findings and to act with conviction in the dissemination of our research. We positively affirm that our research processes must be and are influenced by the cultures of American Indians who have disabilities. We are certain that this awareness, and the research procedures it allows us to create in partnership with community members, allows for the "enhanced validity" of our research. We trust that our research can then demonstrate its value and usefulness to the people whom we aspire to serve as researchers and practitioners.

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